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Useful Stuff

Our Freepost Address

ASSERT Freepost PO Box 4962 Nuneaton CVII 9FD

Our Website www.angelmanuk.org

Email Assert assert@angelmanuk.org

Helpline 0300 999 0102

Assert Families - New Diagnosis Advice Contacts - Support

Assert Shop

Wear your charity with pride! T-shirts, polo shirts, bags, hats and lots more from Spreadshirt, our on-line retailer: http://458768.spreadshirt.co.uk

Front Cover

Photograph courtesy of Robert Chadwick. We'd like to use one of the great photos taken at our 2010 conference on each of our future covers. If your AS family member was one of those photographed and you do not want their images used on Assert material please let us know at the above address as soon as possible.

Contents of the Newsletter

You will notice that the pieces in this newsletter are drawn from a wide variety of sources. While we are keen to promote discussion and to pass on any views and experiences, it is also important to appreciate that the opinions and views expressed by contributors to this newsletter are personal and not necessarily those of Assert.

Letter from the Trustees

Latest research news and Conference 2012

Over the past year there has been much activity in the world of Angelman Syndrome research and this shows no signs of reducing. We currently see the starting of clinical trials in Florida using Minocycline to see what the effects might be on people with AS. Certainly the tests that have been done using mice have been interesting and do indicate that there may well be a biological impact in using this drug which has traditionally been used as an antibiotic in the past. So like everyone else, we eagerly await the outcome of these trials to see what the results are with humans. The study is anticipated to finish in November this year, so as soon as any results are published we will let you know how successful this has been. For more information you can visit the FAST web site. (www.cureangelman.org)

A number of other trials are being undertaken worldwide, including the use of another drug, Levodopa, in the treatment of AS. This medication, which has been used in the treatment of Parkinson's disease, is being tested to see whether it could help AS children in their overall development and reduce the tremor that some of them have. This study is not due to complete until June 2014, but we are again watching with anticipation to see what the results are.

Away from the research side, just in case you hadn't noticed, we have a conference coming up. The trustees are, whilst daunted by the amount of work we have to do, very excited about the conference. We have a number of new speakers coming this year. As soon as we can confirm more of the program we will do, but expect a lot of information on transition and leaving home, a topic which whilst daunting for many we hope we can inform and reassure. I was chatting to a teacher at Ruth's school the other day, who is the schools transition expert, and he said that despite the rumours, for them, pretty much all the children who leave the school do receive the provision they require, and what is more, none of the parents he has spoken to would rather their child returned to the school. Whilst I know this is not always the case, I think generally more is being done, and authorities and agencies are more aware of the need and meeting that need.

And finally, just a quite note regarding local authority cuts, which all of us I think have experienced in one way or another. Recently we found out that the servicing of the equipment that our local authority provides for Ruth will no longer be paid for by them. So if we want it maintained we will have to pay for it. Scandalous is the only word I can use to describe this decision. I contacted the Every Disabled Child Matters team to see if they were aware of this, and they told me they are currently looking into the effects of local authority cuts and welcomed any input on this. So, if your AS individual has been affected by cuts, please contact them to make them aware how. Do not assume that they already know, because in our case, they had not heard of this before.

Anyway, that is enough of me. I hope you enjoy this newsletter, and we look forward to seeing you at the conference.

Regards,

Jeremy Webb

Siblings - Just for Us!

How high can you go?

The drop seemed calamitous, the ground less than secure, the air thin. Fortunately there was no wind but that meant we could clearly hear people screaming below. Two threads kept us from serious injury if not certain death. My companion, after a hesitant start, was getting into his stride. I on the other hand could feel my own confidence beginning to ebb. As I hung pondering the options I realised that I couldn't reverse my steps, the only way was forward but I couldn't see how.

Then a gentle voice of encouragement said very calmly "You can do it, just put one foot in front of the other". I steadied myself and looked up. There was a cheerful face nodding and smiling down at me. She was about eight years old.

A couple of times in the past year I've been out with another AS sibling, someone who is a bit younger than me (ok, he's a lot younger than me) and the idea was to get out, have a break and a chat about whatever. My companion is good at sport, can run fast and talk faster and can do maths better than I could at his age. As we talked I realised that although his circumstances are different in several ways to mine as I grew up our experiences have had many similarities and particularly what it was like to be out and about with our brother/sister and the attention that can often attract. Most people are fine but some people stare or make comments and that can be wearing after a while.

Together my fellow sib and I have been to the National Space Centre and most recently to the high rope-walk at Rutland Water and it also struck me as I looked back that, although we hadn't deliberately planned it, we were doing activities that required getting up as high as we could. I don't think that tells you anything much about us (maybe we like to be above people?!) but it did make me think generally about how far in life it is possible to go.

One of the joys of being part of ASSERT for me is meeting other sibs and hearing what they are up to. I'm always impressed by how outgoing and positive other sibs are. It is also noticeable (and this is borne out to some extent by the research into sibs that I've been looking at) that many grow-up and follow careers in the professions linked to caring. But as I always say, we are all individuals and I delighted that the Trust continues to be committed to supporting siblings to reach their full potential. If you have any experiences you would like to share through the newsletter please let me know.

Russell Andrews



Don't forget our Facebook page:

My brother/sister has Angelman Syndrome

We now have 72 members and it's growing all the time. So if you're old enough to be on Facebook, join us and let's hear from you.

New Young Sibs Club!

Everyone gets a T-shirt!

Well, not **everyone** gets a T-shirt... only special people. If you are under 13 we want to encourage you to send in a piece of artwork or writing (a story, poem, that sort of thing) that we can publish in the newsletter in the Siblings section – it can be about what it's like to be a brother or sister of someone with AS or it can about something that matters to YOU.

And everyone that has something printed can choose between an I'm no Angel! T-shirt or one of the new Smiley Angel designs we're working on (below).

So what have you got to lose?

Send your entries to Russell Andrews either via email to:

Russell.Andrews@angelmanuk.org

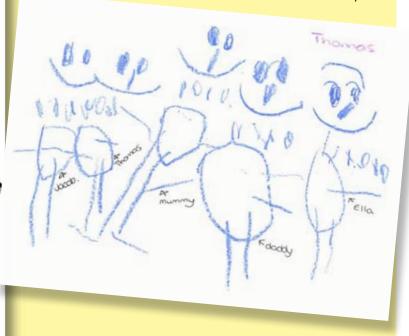
...or by post to:

ASSERT Freepost PO Box 4962 Nuneaton CVII 9FD

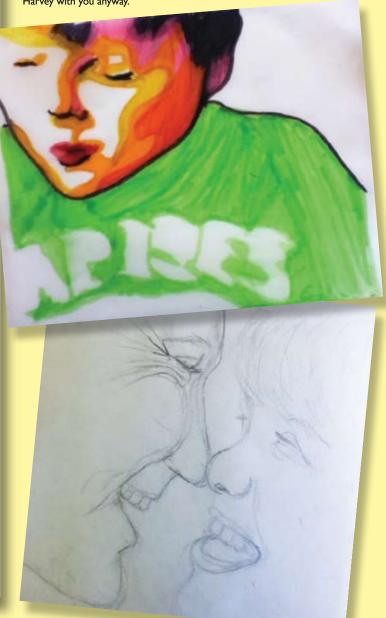
...and don't forget to tell us your T-shirt size!



4-year-old Thomas Court sent us this great picture of his AS sister Ella with the rest of his family..



Lottie Fox-Jones is 16, so doesn't really qualify for a T-shirt, but we thought we'd share these great pictures of her AS brother Harvey with you anyway.



Research Report

The last few months have seen several articles published on the research into treatments that might soon be available for Angelman Syndrome, together with the recent news that human trials for some of those treatments are soon to begin in America. Assert closely follows all research into Angelman Syndrome.

Professor Bernard Dan has very kindly prepared a brief overview of the different ways in which AS can be expressed, some of the current research being carried out and also the implications of that research.

Angelman syndrome is caused by the lack of expression of a small portion of DNA, i.e. the UBE3A gene, in brain cells. This gene is located on chromosome 15. We normally have two intact copies of it in each of our cells, as we inherit two full sets of chromosomes, one from our mother and one from our father.

However, the UBE3A gene is expressed (almost) exclusively from the chromosome 15 we received from our mother and the copy that is present on the chromosome 15 we got from our father is (virtually) not expressed at all.

- Deletion Many people with Angelman syndrome have this condition because the region containing the UBE3A gene on the chromosome 15 they inherited from their mother is missing; this is referred to as a deletion or del 15q11-q13.
- Uniparental disomy Another genetic accident which may cause Angelman syndrome results in having both chromosomes 15 coming from the father and none from the mother: this is paternal (= from the father) uniparental (= from one parent) disomy (= both chromosomes).
- Imprinting defect Yet another genetic abnormality results in not being able to identify the chromosome 15 which is inherited from the mother; this is known as an imprinting defect.
- UBE3A mutation Finally, there may be an abnormality within the sequence of the UBE3A gene; this is a UBE3A mutation.

All these mechanisms give rise to Angelman syndrome, but there may be statistical differences in the severity of the condition according to the underlying genetic mechanism. Some features like intellectual disability, speech impairment and epilepsy tend to be somewhat less severe in individuals who have uniparental disomy or imprinting defect than in those who have a deletion or a UBE3A mutation.

This variability may point to the possibility of residual (if minimal) expression of the gene which is intact, i.e. the copy of UBE3A which doesn't carry the typical 'READ ME' signal that normally marks it as coming from the mother: patients with a deletion or a mutation have one intact (but virtually non-functional) copy of the UBE3A gene, and those with uniparental disomy or imprinting defect have two intact (but virtually non-functional) copies.

For a number of years, several teams have tried to find ways to promote the expression of the intact but non-functional copy of the UBE3A gene. There have been great improvements in the understanding of mechanisms that naturally promote expression of the gene on the chromosome 15 inherited from the mother: This 'READ ME' signal is related to DNA methylation. This has led to various treatment attempts which have all failed to show clearly positive results up until now.

Very recently, a team led by Benjamin Philpot and Mark Zylka in North Carolina used a different approach. They tested more than 2,000 known drugs on a mouse model of Angelman syndrome to see if some of them could activate the non-functional copy of UBE3A. And indeed, among these drugs, a small family of anti-cancer drugs, which are known to affect a specific process related to DNA, has been shown to activate the normally silenced paternal copy of the gene. The most potent drug in this group was topotecan, alias Topo.

When used to treat cancer, it is hoped that this drug alters the DNA in such a way that it can't undergo replication, eventually leading to the death of cancer cells. The property on which Topo treatment is based in that context is thus clearly cytotoxicity, or cell poisoning. The fact that this drug can activate UBE3A may have great implications for developing new strategies of chemical management of Angelman syndrome.

A lot of questions need to be answered before we know if and how these early results in animal experiments can impact individuals with Angelman syndrome; for example: Would the effect of such drugs on UBE3A expression be stable over time? What would be the effect on the manifestations of the syndrome in animal models? What doses would be useful and how should they be given? Which side-effects might there be? When should they be administered? And then how safe, useful and feasible would it be to give them in humans? Only

then would we start exploring whether (and to what extent) drugs such as Topo might alleviate symptoms in individuals with Angelman syndrome.

These are all new questions and the teams, technology, methodology and enthusiasm are already working on them, while keeping in mind that medical science must follow a sound, stepwise road and it is obvious that human trials cannot start before we have firm answers to the preliminary questions.

Professor Bernard Dan

Dept. of Neurology, Hopital Universitaire des Enfants Reine Fabiola, Université Libre de Bruxelles



Ella's Magic Suit

Ella currently has a DM Orthotics suit which she has been using since September 2011 to help with her mobility. Ella's physio recommended the suit to try and progress Ella with her walking. Ella could walk with assistance and was standing independently for a couple of seconds, but had got to the point where she would not make the next step (literally) to try and take some independent steps. Ella's physio had used a similar suit with other children who did not have AS, but the theory behind it meant that it could / should also help Ella. At a cost of £540 I did expect the suit to arrive with a few diamonds sewn into it, as it seemed a huge amount of money for what looked like a very thin wet suit!

The idea of the suit is that it helps with posture, but that it will also give Ella that feeling of security in that she will feel very supported (as the suit is intentionally snug) and give her the confidence to take some independent steps.

I happened to go to 'Kidz in the Middle' last year, and DM Orthotics were there, so I spoke to them about the suit. I then went to all the charity stands with the information asking if they would consider funding a suit. Newlife said yes, so I sent off an application form. Although it was agreed they would fund the suit, they had no funds available so we ended up having to do an article in the local paper: embarrassing as obviously the story they printed was nothing like what I told them, but then I am used to that by now. We only had £40 donated, but we were very lucky in that the church that Ella's taxi escort attends offered to fund the difference, so they donated £500.

The suit is made to measure and so the physio for DMO had to come round and take an abundance of measurements from Ella. As you can imagine, that wasn't an easy task! Ella thought it was just one big tickling game and every time he put a tape measure near her she would wriggle around laughing and refuse to keep still. The suit had to be returned a couple of times for alterations because Ella was so difficult to measure. We received the final version at the beginning of September. Ella wears the suit about 12 hours a day – I put it on her when I get her dressed in the morning, and take it off when she has a bath (she doesn't wear it over night).

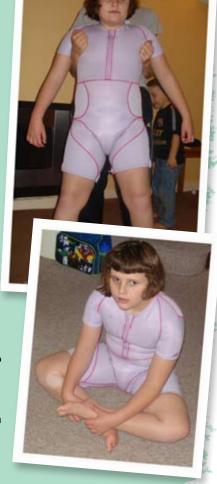
Since having the suit, Ella has been having extra physio sessions at school to give her maximum opportunity to progress. In 6 months she's has gone from not really wanting to stand independently and certainly not wanting to walk independently to being able to stand for long periods of time unaided, and to consistently take a number of steps unaided. We are now up to 39 steps unaided which is an absolutely huge achievement for Ella. I don't think she's ever progressed at anything so quickly. In 6 months she has gone from nothing to consistently walking several steps which is just amazing. We have no idea whether Ella will ever independently walk, but we are certainly doing everything we can to give her the best possible chance, and I strongly believe that this suit is going a long way towards this.

For more information, please see the website: www.dmorthotics.com

Please note that Newlife have now changed their criteria and will no longer fund a DMO suit.

Lisa Court





Dates for your diary...

Kidz South – Thursday 14th June 2012 Rivermead Leisure Complex, Reading

Kidz Up North – Thursday 29th November 2012 Reebok Stadium, Bolton

Kidz in the Middle – Thursday 28th March 2013 Jaguar Exhibition Hall, Ricoh Arena (too late to advertise this year)

New and coming soon – Kidz Scotland 2014 date to be confirmed. www.kidzexhibitions.co.uk Here's something we think a lot of you might be interested in. They're expensive, but if they're just what you're looking for you might be able to get funding from a local authority or charity to help with the cost. Let Assert know how you get on if you try them.

Tomcat

Special Kit for Special Kids

Tomcat Twisters™

Here at Tomcat, we meet lots of families who find it difficult to find suitable footwear for their child, especially if they use splints or AFOs. Some have to buy two separate sizes, or have to struggle every morning to get shoes or boots over splints, which can be painful for everyone involved! Tomcat discovered these special shoes whilst in Italy. We were there showing people our custom built tricycles at the time (which you may know us better for!). When we saw what they could do, we couldn't wait to show our customers and hopefully ease a lot of the footwear problems faced by parents.

Tomcat Twisters ™ are specifically designed for splint or AFO wearers and those with arthritis or fine motor problems. Styled as designer sports shoes, Twisters have an innovative lacing wheel behind the heel instead of conventional laces. The lace wire is guaranteed for the life of the shoe.

Tomcat Twisters[™] take just seconds to fit and are always snug and supportive whether the foot is in splints or not, because Twisters automatically adjust themselves to conform to the shape of the foot from heel to metatarsal. Because of this unique feature, specially sized shoes are unnecessary.

Orthotists can reshape the Twisters' sole if the foot is pronated or supinated by heating then peeling back the VIBRAM rubber sole and reshaping the EVA midsole by adding or removing material. Orthotic insoles can also be used.



Winter Twisters have all leather uppers in two standard colours, and summer Twisters have leather ventilated and composite panels, also in two standard colours. All shoes are leather lined.

Tomcat Twisters™ are beautifully made by one of Italy's leading orthotic footwear manufacturers and exclusively distributed throughout the UK by Tomcat SNI Ltd. Sizes are available from child sizes 7-13, and adult

sizes 1-5, including half sizes and each shoe will self-adjust over four foot widths.

If you have any questions, please do get in touch!

Telephone 01452 616 900 Email: info@tomcatuk.org

Or see www.tomcatuk.org/Tomcat-Twisters

for more information, photographs and an order form.

How does it work?



Regional Meetings

Central Meeting 5th November 2011

A regional meeting was held in the central region on Saturday 5th November 2011, at Dorothy Goodman School in Hinckley, Leicestershire.

A number of families attended and there was a lovely mix of old and new faces. It was the first regional meeting since the conference, so there was the usual catch up of what's been happening with everyone over the previous 12 months, and obviously a great opportunity for new families to chat and ask advice.

Charlotte from Cerebra made a presentation on what Cerebra can offer in 2012 and how they can help our families.

There was the usual routine of a children's entertainer to keep the kids entertained (and she did a good job entertaining the adults as well!). Everyone enjoyed a buffet lunch and made the most of the opportunity to sit and have a chat.

As always, the children thoroughly enjoyed making the most of the facilities in the soft play room and sensory room – it's amazing how

many children and adults you can squeeze into a soft play area when you need to!

Hopefully it won't be too long before the next regional meeting and all families are very welcome to attend.

Lisa Court





Southern Meeting - 26th November 2011 Paultons Park – Winter Wonderland

We had a fantastic turn out for the last Southern Meeting (21 families – about 90 people if my memory is right). A brief overview for those of you who couldn't be there...

After a quick chat at the gate we started off by having lots of fun going round the park on all the rides. Most of us managed to meet up for lunch, and then after more rides we joined the queue to see Father Christmas. It was a slightly strange Christmas scene (not sure where dinosaurs and giant tigers fit into Christmas) but it didn't seem to put anyone off. A small competition was arranged among our Angels to see who could remove Santa's beard quickest (sorry I can't remember who won) and then after comparing presents we all went home.

Thanks to everyone who came, and hopefully I will arrange it again this year – with enough space for everyone for lunch this time!

Katie Cunnea



Hannah Pickering wrote this piece as part of her A-level Psychology course. We thought it might be of interest to our families.

The Life of an Angel

It was 2002 and our family had known something wasn't right with my sister, Livvy, for a number of years. She was 5, I was 9. It didn't take a genius to realise that she wasn't going to be 'normal', but somehow I didn't care. The doctors had gone through numerous possibilities of what disability Livvy was going to be labelled with during the first 5 years of her life. Finally, a breakthrough! Angelman Syndrome they said; a neuro-genetic mental disorder once known as 'happy-puppet syndrome'. Although it wasn't great news as she was going to have to live with this severe learning disability for the rest of her life, at least we knew what she had, so we could start to attempt to address the problems.



The Boy with the Puppet Giovanni Francesco Caroto

If I said Autism or Down Syndrome, most people would be able to somehow relate to the disability. However, with only about 350 people having been diagnosed with Angelman Syndrome (AS) since the identification of the disability in 1965 within the UK, it doesn't surprise me when people haven't a clue what I'm going on about when the ask: "What's wrong with your sister?" When I began to research AS a few years ago I stumbled across a picture which Dr Harry Angelman, who first identified the disability, used to illustrate AS. 'The Boy with the Puppet' by Giovanni Francesco Caroto gives those with little knowledge of AS a quick idea about the happy demeanour to expect from an 'Angel'. Throughout I won't refer to livvy's disability as a mental disorder, although technically speaking it is, I feel a disability is a better characterisation, as I don't believe her to be 'mental'; she's just Livvy.

What causes Angelman Syndrome?

Angelman Syndrome can be caused by varying ways, my sister has the most severe form; deletion. Around 70% of AS sufferers have this form of the Syndrome. Healthy people have two chromosome 15 contributions, one from the father, one from the mother. Deletion is when the mothers' contribution to chromosome 15 is lost, or deleted. This

causes the chromosome to have disruptions in regions, and it is believed to then have a lasting effect on delay in both mental and physical development. Although as of yet it is still not understood what exactly the part of chromosome 15 affected does within the body, research is being completed slowly.

How is it characterised?

Livvy has the consistent (100%) deletion form of AS, this means that she has various clinical features that make it

different to the Associated (20-80%) or Frequent (80% or more). Although she possesses most of the characteristics of the associated and frequent severities of AS such as hyperactive tendon reflexes, sleep disruption, fascination with water – Associated features. Some frequent features are seizures, often as a result of epilepsy that is a main feature of the syndrome. Also, abnormal EEG (brain) patterns, these have slow-spike waves with large amplitudes at irregular intervals rather than more regular patterns with a repeating pattern that does not vary, which have regular spike waves at lower amplitudes than those with AS.

Livvy's main characteristics of AS are a developmental delay, this is quite self-explanatory but she is (as I will discuss later) behind mentally and physically compared to her normal age. Physically her hands and feet are small compared to her height. Her head growth is delayed slightly, although not as severe as



other sufferers. Therefore she has slight microcephaly, which is a neuro-developmental disorder where the head is smaller than that of average people her age. In addition she has problems with balance and movement which means her co-ordination is limited. Livvy is lucky in comparison to other sufferers, although told by the doctors that she would never be able to walk, she is now mobile to an extent due to an amazing physiotherapist who pushed her to walk. Most sufferers (about 90%) are immobile and are wheelchair dependent. Behaviour is very unique in AS sufferers and Livvy always has a happy demeanour with frequent laughter and you will rarely find her without a smile on her face. Although with age she is beginning to get a mind of her own and often becomes agitated which results in anger and aggression involving hitting out at those around her.

One of the major characteristics is that she has no verbal speech, and with it being a severe mental disorder she finds it hard to respond with sign language as she has the mental capacity of a young toddler. However knowing her for 13 years has its advantages, in most cases I can always tell what she wants or is thinking by her facial expressions, or by her general behaviour. As her character has developed over the years, this has enabled her to use non-verbal communication to make up for the limited speech.



Mental Ability

In terms of mental ability, following the Vineland Adaptive Skills Survey filled out when Livvy was 12 years and 9 months, we were able to find out the

true mental capability of Livvy. This survey is a behavioural survey that helps to determine the mental capability of an individual. It is also used to help doctors with diagnosis of various developmental disorders. The results from the survey are shown below (taken from the write up of the survey):

'An overall domain standard score is calculated by adding the scores from the three major groups...describes Olivia's overall functioning. Olivia's overall score of 36 means that she falls into the "moderate deficit" classification of functioning.'

	DOMAIN STANDARD SCORE	90% CONFIDENCE LEVEL	CLASSIFICATION
COMMUNICATION	34	27-41	Severe-Moderate
DAILY LIVING SKILLS	40	32-48	Severe-Moderate
SOCIALISATION	42	35-49	Moderate
OVERALL FUNCTIONING	36	35-49	Moderate



Converting these into ages we were told that Livvy's receptive communication was around the age of I year and 3 months, the expressive communication was about 9 months, and the written was about 2 years 5 months. These therefore show that communication wise she has an average age of about 18 months, which is significantly below her actual age of 13. However, these may increase with age and experience. When looking at the mental capacity, it is the communication that is a large indicator as when comparing to normal people it is the communication that leads to daily living skills and socialisation; it is often a basis to basic life skills. When looking at daily living skills, her average age conversion is 20 months, and when looking at socialisation her average age conversion is just under a year. This therefore shows the link between communication skills and the latter two, as they are all similar in age

range. Although, looking at this, it is surprising as I would view her socialisation skills as higher than anything else, this may be true, as the survey is not 100% valid.

Is there any treatment?

There is no treatment for any of the forms of Angelman Syndrome to date (*Please see elsewhere in this issue for the latest updates on research and treatments - Ed) and most psychologists believe that there will never be any way for it to be fully treated. The best way to help deal with the Syndrome is to try and treat the symptoms or reduce the effects it causes. For example, most suffer from epilepsy, and this can be controlled by taking doses of medications that are anticonvulsant. However this often takes years to find the right dosage and changes at least twice a year whilst the sufferer is still growing. With the sleep disruption, which varies in severity, melatonin is used by most sufferers' families to promote sleep and to maintain sleeping patterns. To keep mobility to a high and decrease the chance of being wheelchair bound, physiotherapy is advised to be started as early as possible. In Livvy's case the latter proved to be beneficial.

Now 13 it's not as if Livvy's had a bad life, if anything she's had all the luck in the world! Her disability has never stopped her, she's always willing to try new things; in other words we sign her up for everything! Her latest adventure is a skiing trip, going for the second time in February with her school. Looking back, I never thought she'd ever be able to do something so adventurous, but I guess you can't let things in life stop you from living life to the full.



- DOWATIONS -

Thank you to everyone who has donated to ASSERT.

Your contributions - no matter how small - all make a difference. Without you there would be no ASSERT and we know how important we are as a support to our families within the AJS community. Many thanks to:

Mrs Eyre & Mrs Myers

Mr Layer

Mr & Mrs Rose

Lisa Smith (Birthday donations)

T Harrell

Mrs Tait

Heptonstalls LLP Solicitors

Alan & Jennifer Forsyth

Daniel & Judith Williams

The Buzzacott Stuart Defries Memorial Fund

Mr & Mrs Simpson

Mr & Mrs Hills

Emma Glasgow

Mr A J Taylor

The Royal Sussex Chapter 342

Cruden Property Services Ltd

Mr & Mrs Webbing

T K Ray

Mr & Mrs Cash

Last word ...

Don't forget you can also support Assert by buying from our great range of T-shirts and other gifts.

You can find our on-line shop through the link on our new website or by going directly to:

http://458768.spreadshirt.co.uk

